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Chapter 6

Summary and General Discussion



The overall aim of this thesis was to gain insight in factors associated with the connection between parents with MID with potential support needs and those who might be able and willing to provide such support. The current study focused on parental support needs, the quality of working alliances between parents and staff, mindset of staff and the role of informal support as possible contributors to willingness of parents with MID to ask and receive support. The studies in this dissertation were aimed to contribute to a better understanding of how to strengthen the connection between needs of parents with MID and the support that services can provide.

The samples of the studies as described in Chapters 2 through 5 were part of a core sample of 146 parents with MID, who were recruited among the clients of 10 care organisations for people with intellectual disabilities (ID) in the Netherlands. Parents filled out questionnaires and participated in interviews during home visits, staff supporting the parents filled out questionnaires. Finally, 117 informal network members of parents from the study sample participated in a survey study.

In this final chapter, findings from Chapters 2 through 5 are summarized and discussed. Then, findings are placed in the context of the strengths and limitations of the study, followed by implications of this study for future research and practice. This chapter is closed by a general conclusion to this thesis.

Findings and conclusions

Perceived parenting stress of parents with MID

The connection between parents with MID and services may primarily be driven by the extent to which parents feel a need for support. Therefore, **Chapter 2** tested to what extent parents with MID experience that their own resources fall short of what is required to parent well, by focusing on parenting stress as experienced by parents with MID as an indicator of need for support. Previous research has examined parenting stress as a global construct, which may contribute to continuing misunderstanding between parents and support figures, if the areas of stress from parents' perspective do not match with the areas that professionals assume are affected. Therefore, this study unpacked parenting stress by distinguishing between parenting stress attributed to oneself as a parent (parent domain) and parenting stress attributed to the child's behaviour (child domain). Results indicated that parenting stress attributed to children's behaviour was higher than parenting stress attributed to oneself as a parent among parents with MID. This suggests that parents do experience a need for support concerning their child's behaviour, more than concerning their own role as a parent. Furthermore, only stress on the child domain was associated with child behaviour

problems, while in the general population child behaviour was associated with stress with regard to the parenting role. This suggests that parents with MID might be less inclined to attribute their child's difficulties to their own capacities or to the family situation. Parenting stress from the perspective of parents with MID thus appears to differ from parenting stress as reported on in the literature on parents without MID.

With regard to the factors that were associated with parenting stress, a multifactorial model appeared most appropriate. Not only child behaviour problems, but also a lack of financial resources was associated with higher levels of parenting stress. While child behaviour and economic burden have been widely reported as stressors for parents, the current study contributed to previous research by testing combinations of stressors and resources in relation to parenting stress. These in depth analyses revealed that the association between parenting stress on the child domain and child behaviour problems was buffered by access to support figures and, to a lesser extent, by parental adaptive functioning. It should be noted that only in this regard adaptive functioning of parents with MID played a role as a buffering factor for parenting stress, while contextual factors appeared to be involved more broadly.

Support seeking and working alliance

Parental preferences in support seeking are a possible indicator of the quality of the connection between parents with MID and staff. **Chapter 3** tested if parents who feel a need for support actually ask for support and, if they do, how readily they turn to professionals or to informal support figures. Parents appeared to prefer informal support figures over professionals. Parents with a higher need for support, that is higher experienced levels of parenting stress, waited less to ask for support with professionals than parents with a lower need for support. This is consistent with previous research which indicated that accurate appraisal of one's own resources to address challenges is associated with adequate patterns of support seeking (Cohen, 1999). Parenting stress is generally seen as a risk factor for parenting and child outcomes (Deater-Deckard, 1998). However, parenting stress has also shown to fulfil the role of motivator for change (Abidin, 1992) through stimulating parental support seeking for problems that surpass perceived competence. Such motivation to change and to seek and accept help may only lead to positive outcomes if it is positively responded to by the social environment.

The connection between parents with MID and services appeared to depend on interpersonal factors as well. Over and above the association between parenting stress and parental support seeking, higher working alliance quality was associated with a shorter waiting time to approach professionals for support in difficult child rearing situations. This finding applied most strongly to the most vulnerable parents, that is

the parents with little access to informal support. These findings converge with other studies on determinants of support seeking. When stress, risk factors, and lack of personal resources combine (e.g., lower emotional competence; Ciarrochi & Deane, 2001), effective support use becomes more dependent on external factors. The present findings indicate that when access to informal sources of support is low, at risk parents do not turn to professional support by default, but may require a trusting relationship before doing so even more than parents with ample access to informal sources of support.

Support seeking and mindset of support staff

If interpersonal factors are important for the connection between parents with MID and services, not only parent characteristics but also characteristics of the staff supporting parents with MID are important to examine. **Chapter 4** reports on staff mindset as a possible determinant of working alliance quality. Based on mindset theory (Dweck, Chiu, & Hong, 1995) it was tested whether staff held the idea that parenting skills of parents with MID can change (incremental mindset) or are static (entity mindset). Among the sample of this study, there was a group of staff who appeared not to be convinced about the possibilities to improve parenting skills for parents with MID. This finding is of special importance given the evidence from this study that working alliance quality appeared to be less strongly associated with parental adaptive functioning if staff believed more strongly in parental possibilities to change parenting skills. Moreover, parents with MID intended to wait less before they asked professional support if staff was more convinced about parental possibilities to change parenting skills.

Negative attitudes of others towards parents with MID have been hypothesized as a challenge to parenting (Aunos & Feldman, 2002). The findings in chapter 4 give clear directions about how negative attitudes of others might not only be an unpleasant experience for parents, but also disturb the connection between parents and services. The findings indicate that a long waiting time to approach professionals, which is regarded as a risk factor for parents with MID and their children, might partly be explained by staff factors. Staff mindset could then be important to bridge the gap between parents with MID and services.

Support seeking and informal support

In the field of child and social welfare, the concept of empowering informal networks has been emerging to address social problems. Therefore, and because of the fact that parents with MID appear to prefer informal support over formal support, factors impeding or promoting the connection between parents with MID and their informal

network members have been studied in **Chapter 5**. Mothers of parents with MID appeared to see themselves as a source of multiple types of support, more than sisters or partners of parents with MID. In addition, mothers appeared to be less likely to adjust their support to parental signals of need for support, and more to possible risk factors for their child or grandchild.

With regard to factors associated with supporting parents with MID, findings in chapter 5 indicate that for different network members (e.g., partners, mothers, sisters) different factors might impede or promote the support they provide. Mothers of parents with MID appeared to offer more support when hypothesized barriers for support were high, that is when parents felt less comfortable to ask and accept support, when relationship quality was lower and when the geographic distance to the parent was larger. The support that sisters provided to parents with MID appeared to depend more on parental signals, sisters provided more support when parents waited less to ask for support. Although the exploratory nature of the study must be taken into account, it might be that mothers adequately interpret the hypothesized barriers for support seeking as possible risk factors for parents with MID. Mothers might then take a pro-active approach in providing support to their daughter. Furthermore, the relationship between sisters might be more equal than the relationship between mothers and children with MID.

Strengths and limitations

The sample of the present study, particularly the samples of Chapters 2 and 3, was large compared to other studies on parents with MID. The relatively large sample size enabled us to conduct moderator analyses, which are still scarce in the field of intellectual and developmental disability research (Farmer, 2012). Until now, theoretical models (Aunos & Feldman, 2002) and studies on parents with MID have been built upon and testing singular and isolated associations. Looking at one factor at a time yields no insight in the synergy among factors affecting parenting by persons with MID. With the moderator analyses more insight was achieved into individual differences among parents with MID. The current study showed that it is important to differentiate between parents with high and low (informal) support and parents with high and low parental adaptive functioning when assessing or describing parents with MID.

Another contribution of the current thesis is the multi-informant design, with a combination of parent, staff, teacher and network member reports. This design ensured that the findings of the current study could not be assigned to participants'

answering tendencies, for example because of parental mental state. Furthermore, with the multi-informant design it was possible to combine and compare different perspectives on family and support situations of parents with MID.

The results of the present thesis must be considered in the context of limitations of the research design. Due to the cross-sectional nature of the data, no definite conclusions can be drawn about the direction of the associations. A reversed direction of the associations as found in the current thesis might also be plausible. Therefore, causal interpretations of the current findings can only be made in a highly tentative fashion.

Another limitation can be found in the fact that, despite the relatively large size of the sample, the sample only represented parents with MID served by care organizations for persons with intellectual disabilities. Parents with MID who did not receive services were not included due to the sampling method. The fact that these parents were not included in this thesis limits the generalizability of the findings. Parents with MID who did not receive professional support might be families who fared quite well because of larger informal support networks or higher levels of parental adaptive functioning. In contrast, the families not included in this study might be families who rejected all professional support and who are the hardest to reach by professionals.

In addition, the models as included in this thesis explained moderate amounts of variance in outcome variables. The (significant) R^2 values ranged from .10 (in Chapter 2) to .25 (in Chapter 4), meaning that 75 to 90 % of the variance in outcome variables was not explained. Including other factors, such as indicators of quality of support and parental mental health would have been useful in explaining factors associated with support seeking by parents with MID.

Directions for future research

The current findings contribute to building causal models on the ways in which need for support, working alliance quality, and staff mindset impact the quality of the connection between parents with MID and the services supporting them. To test the causality of the associations in the model, studies with longitudinal and experimental designs are required. By studying pathways of interactions between parents and support staff over time, points of action for interventions to bridge the gap between parents with MID and services that are hypothesized in the current thesis could be established and affirmed.

Furthermore, study designs which include observations of staff behaviour are advised. The current study does not explain how staff mindset might decrease associations between parental adaptive behaviour and working alliance and why parents wait

less to ask for support with staff that holds an incremental mindset. Furthermore, it is unclear how a good working alliance quality might promote parental support seeking. Staff behaviour might be the mediating variable between mindset, working alliance and parental support seeking.

Implications

Scientific implications

The current thesis has yielded new findings that contribute to the model regarding parenting by persons with MID as proposed by Aunos and Feldman (2002). In their parenting interactional model, Aunos and Feldman (2002) already stated that “parenting difficulties of people with intellectual disabilities is not solely a function of their cognitive limitations” (p. 291). The current thesis adds to this model by showing that also in the connection between parents and services, contextual risk and protective factors appear to be of greater importance than parental characteristics such as adaptive functioning. Based on the current results, distinguishing between parents based on their level of adaptive or intellectual functioning appears of minor concern as to consider the marginal position of parents with MID in society and the quality of the services that are provided to them.

Furthermore, the results of the current thesis give substance to the “interactional” aspect of the model as proposed by Aunos and Feldman (2002). The model was called interactional because “numerous ... factors will affect parenting style and child outcomes in families where the parent has ID” (p. 291). The current thesis adds to the interactional nature of the model by showing that factors not only together affect parenting by persons with MID, but also interact with each other and the effect of risk factors might be conditionally determined by the presence of buffering factors.

Another contribution of the studies in this thesis concerns the conceptualization of the connection between parents with MID and professional support services. While this concept has been recognized as important by professionals in the field (Willems, De Vries, Isarin, & Reinders, 2007) and may play a role in legal decision making with regard to protection of the children in these families (Kemp, Marcenko, Hoagwood, & Vesneski, 2009), there is scant work that has operationalized and studied this concept beyond studying engagement when agencies are already involved. The findings in Chapters 2, 3, and 4 show that the concept can be tapped in a useful manner by asking parents to respond to concrete scenarios of situations that parents find challenging. Comparing responses to scenarios taken from parents’ own experiences and standardized hypothetical scenarios suggested that psychometrically, working with

standardized scenarios yields more reliable results. However, including parents' own concrete experiences in the assessment may have contributed to rapport with the interviewer and helped parents to relate to the hypothetical scenarios. Therefore, these scenarios may remain a useful addition to the Support Interview Guide (Llewellyn & McConnell, 1999) in which these were embedded.

Implications for practice

The findings from the current thesis also have implications for practice. Staff involved with support for parents with MID have been shown inclined to describe their clients as difficult to reach and non-cooperative (McConnell, Feldman, Aunos, & Prasad, 2011). The findings of the current study show various avenues through which the field of practice might strengthen the connection with parents with MID. Parental disengagement might not exclusively be a parent characteristic, but be a characteristic of the relationship between parents and professionals, which may be changed by either part. In addition, practice is more and more obligated to work evidence based and to restrict their support offers in time and money. This development forces care organisations to justify their choices regarding staff behaviour and support arrangements. The current results might provide care organisations with arguments by showing the importance of investing in the quality of relationships and by showing that it might not be the quantity of support but the quality of support that matters.

Findings described in Chapters 2 and 3 stress that a functional-contextual approach (Benjet, Azar, & Kuersten-Hogan, 2003) to assessment and support of parents with MID is necessary. In Chapter 2, the potential protective abilities of financial and social resources against the effect of stressors were highlighted. In Chapter 3, reluctance to seek support, which is seen as a risk factor for parents with MID, was partly explained by having ample social resources. These findings connect well with the need to assess parenting capacity by evaluating both parenting skills and considering the role of contextual resources (McConnell & IASSID, 2008). Furthermore, efforts are called for to strengthen contextual resources for parents with MID. Interventions to strengthen supportive networks for parents with MID have been developed and showed improvements in parent psychological well-being by improving social support (Darbyshire & Kroese, 2012).

Findings described in Chapter 3 showed that a good working alliance was associated with less parental reluctance to ask for professional support for parents with small informal support networks. These findings suggest that the connection between support programs for parents with MID and the parents might be improved by an integrated focus on the quality of relationships between parents and staff. The concept

of working alliance, with its components of bond and agreement on tasks and goals, provides important concrete leads for improving the quality of relationships.

Building a good working alliance for supporting families with a parent with MID might start from a shared concern towards child behaviour difficulties. Findings described in Chapter 2 indicated that parents with MID appeared vulnerable to experience parenting stress attributed to the challenges presented by the child, not the challenges presented by their own capacities or the family situation. With shared goals and tasks being a vital component of a good working alliance, child well-being could be a joint goal for parents and staff. A good working alliance based on this joint goal may be an avenue to explore with parents also other aspects of their own functioning and that of their family which may benefit themselves and their children.

Efforts to improve working alliance quality between parents with MID and staff may benefit from taking account of the findings on staff mindset in Chapter 4. Parental adaptive functioning and working alliance quality were less strongly interrelated when staff believed more in parental possibilities to change their parenting skills. If this association can be shown to be causal, that would mean that by improving staff expectations, parents with lower levels of adaptive functioning might have better chances to experience positive working alliance. With this study, the need to pay attention to mindset of direct support workers was highlighted, together with a need to explore options to change staff mindset. Other studies, within the broader research tradition on mindset theory and consequences for behaviour, have tried to change mindset by priming (Bhanji & Beer, 2012; Moorman & Pomerantz, 2010). Future research should focus on predictors of mindset for staff of parents with MID, providing clinical practice with approaches to change the mindset of this specific group of staff.

General conclusion

The overall aim of this thesis was to gain insight in factors associated with the connection between parents with MID and those who might be able and willing to provide support. Until now, studies have done valuable work by identifying the gap between parents with MID and services and hypothesized possible contributing factors. The current study has provided the scientific and clinical discussion of this issue with empirical data.

Findings in Chapter 2 identified a self-perceived need of parents with MID for support, especially when children show behaviour problems. Given the concern that exists over the development of children in families where one or more parents have MID, this provides a point of converging interests with professional support workers.

However, parents experienced this need related to child difficulties and less to their skills and resources as a parent and a family, which is different than found in populations of parents without MID who present with services. By taking this difference in perception into account when establishing a working relationship with these families, misunderstanding and initial disengagement may be avoided. Findings in Chapter 3 highlighted that vulnerable parents, with little informal support, appeared to transfer their need for support to a request for support towards professionals, but only under the condition of a good relationship. Asking support when difficulties pile up, higher than the resources that are available, might be a brave decision that can only be made within a context that is perceived as secure. The findings in Chapter 4 indicated that staff characteristics are a possible determinant of the connection between parents with MID and services. Chapter 5 broadened the focus of this thesis to the connection between parents with MID and informal networks. Findings of Chapter 5 indicated that for different network members (e.g., partners, mothers, sisters) different factors might impede or promote the support they provide.

Overall, the results of the current study indicate that opportunities for bridging the gap between parents with MID and services appear to exist that may be, at least in part, within control of care organisations and staff supporting parents with MID. Within a period where development of evidence based support for people with MID is the point of focus, the current thesis addressed an important condition for providing evidence based support. Hopefully, these findings will provide a starting point to strengthen connections between parents with MID and services and to further study factors involved with wellbeing of parents with MID and their children.

References

- Abidin, R. R. (1992). The determinants of parenting behavior. *Journal of Clinical Child Psychology, 21*, 407-412. doi: 10.1207/s15374424jccp2104_12
- Aunos, M., & Feldman, A. A. (2002). Attitudes towards sexuality, sterilization and parenting rights of persons with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 15*, 285-296. doi: 10.1046/j.1468-3148.2002.00135.x
- Benjet, C., Azar, S. T., & Kuersten-Hogan, R. (2003). Evaluating the parental fitness of psychiatrically diagnosed individuals: Advocating a functional-contextual analysis of parenting. *Journal of Family Psychology, 17*, 238-251. doi: 10.1037/0893-3200.17.2.238
- Bhanji, J. P., & Beer, J. S. (2012). Taking a different perspective: Mindset influences neural regions that represent value and choice. *Social Cognitive and Affective Neuroscience, 7*, 782-793. doi: 10.1093/scan/nsr062
- Ciarrochi, J. V., & Deane, F. P. (2001). Emotional competence and willingness to seek help from professional and nonprofessional sources. *British Journal of Guidance & Counselling, 29*, 233-246. doi: 10.1080/03069880124843
- Cohen, B. Z. (1999). Measuring the willingness to seek help. *Journal of Social Service Research, 26*, 67-82. doi: 10.1300/J079v26n01_04
- Darbyshire, L. V., & Kroese, B. S. (2012). Psychological well-being and social support for parents with intellectual disabilities: Risk factors and interventions. *Journal of Policy and Practice in Intellectual Disabilities, 9*, 40-52. doi: 10.1111/j.1741-1130.2012.00326.x
- Deater-Deckard, K. (1998). Parenting stress and child adjustment: Some old hypotheses and new questions. *Clinical Psychology-Science and Practice, 5*, 314-332. doi: 10.1111/j.1468-2850.1998.tb00152.x
- Dweck, C. S., Chiu, C. Y., & Hong, Y. Y. (1995). Implicit theories: Elaboration and extension of the model. *Psychological Inquiry, 6*, 322-333. doi: 10.1207/s15327965pli0604_12
- Farmer, C. (2012). Demystifying moderators and mediators in intellectual and developmental disabilities research: A primer and review of the literature. *Journal of Intellectual Disability Research, 56*, 1148-1160. doi: 10.1111/j.1365-2788.2011.01508.x
- Kemp, S. P., Marcenko, M. O., Hoagwood, K., & Vesneski, W. (2009). Engaging parents in child welfare services: Bridging family needs and child welfare mandates. *Child Welfare, 88*, 101-126.
- Llewellyn, G., & McConnell, D. (1999, July). *Sharing the care: The Support Interview Guide*. Paper presented at the 11th Australasian Human Development Conference, Sydney.
- McConnell, D., Feldman, M., Aunos, M., & Prasad, N. (2011). Parental cognitive impairment and child maltreatment in Canada. *Child Abuse & Neglect, 35*, 621-632. doi: 10.1016/j.chiabu.2011.04.005
- McConnell, D., & IASSID. (2008). Parents labelled with intellectual disability: Position of the IASSID SIRG on Parents and Parenting with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities, 21*, 296-307. doi: 10.1111/j.1468-3148.2008.00435.x
- Moorman, E. A., & Pomerantz, E. M. (2010). Ability mindsets influence the quality of mothers' involvement in children's learning: An experimental investigation. *Developmental Psychology, 46*, 1354-1362. doi: 10.1037/a0020376
- Willems, D. L., De Vries, J. N., Isarin, J., & Reinders, J. S. (2007). Parenting by persons with intellectual disability: An explorative study in the Netherlands. *Journal of Intellectual Disability Research, 51*, 537-544. doi: 10.1111/j.1365-2788.2006.00924.x